

Children and young people with cancer

A guide for parents



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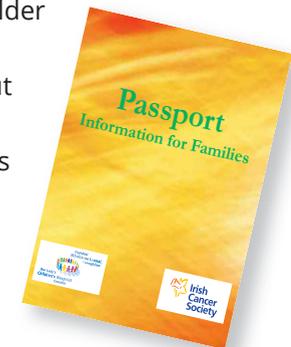
This booklet has been written to help you and your family after your child has been diagnosed with cancer. It has been developed with the help of the staff in the National Children's Cancer Centre (NCCS) at Children's Health Ireland (CHI), Crumlin. This is the national referral centre for all children with a cancer diagnosis in Ireland.

It is likely that you will have lots of questions and concerns both after the diagnosis has been confirmed and as your child goes through their treatment. Your child's consultant and the rest of the hospital team will be your main source of information and support.

However, we hope this booklet will help you too. It has information on:

- Common childhood cancers
- The hospital and who you will meet there
- Tests and treatments your child may need
- Support available after diagnosis
- The impact of a cancer diagnosis on your child and the rest of your family
- Support groups, helpful websites and booklets

You will also be given an information folder – called **Passport** – to use throughout treatment. It contains information about your child's diagnosis and treatment. Together, these will be helpful resources for you and your family.





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Reading this booklet



This booklet aims to help you throughout your child's cancer treatment. Remember, you don't need to know everything about childhood cancer straight away. You will probably find different sections useful at different times. If you don't understand something that has been written, discuss it with your child's doctor or nurse. It is often useful to write down questions as they arise, so you can remember to ask a hospital team member later.

Useful numbers

Children's Health Ireland at Crumlin	01 409 6100
St John's Ward	01 4554 176
	01 4096 654
	01 4096 660
Haematology/Oncology Day Unit (HODU)	01 409 6649
Parents' Accommodation Unit	01 409 6622/6520
Ronald McDonald House	01 456 0435
Family doctor (GP)	
Hospital records number	

Support Line Freephone 1800 200 700

About childhood cancer

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First reactions

Although many children with cancer can be cured, it is still devastating to hear that your child has cancer. Both you and your child will have many different feelings and emotions. These may include fear, denial, sadness, guilt and anger. You may feel numb or like you've been physically hit. These are all normal reactions.

When a child is diagnosed with cancer, it has a big impact on all the family. Your child's routine is likely to change. They may have to stay in hospital for treatment and are likely to have regular hospital appointments. This can be overwhelming for you, your child and the rest of the family. But there are many healthcare professionals and support organisations that can help you through this difficult time.

Why did my child get cancer?

The causes of childhood cancer are still unknown but research is ongoing. It is important to remember that it's not your fault your child has cancer and it is not because of anything you've done or not done.

Most cancers are not caused by an inherited faulty gene and it is very rare for another child in a family to develop cancer. Siblings (brothers and sisters) usually do not need to be tested. Cancer is not infectious and cannot be passed on to anyone who comes into contact with your child.

Childhood cancers

Cancer in children and young people is rare. In Ireland, about 200 children under the age of 16 are diagnosed with cancer each year. In older teenagers, aged between 15 and 19, about 70 cases are diagnosed each year. See page 9 for more about individual cancers.

What is cancer?

Cancer is a disease of the body's cells, which are the building blocks of your body. Cancer can occur in different parts of the body. In fact, there are more than 200 different types of cancer, each with its own name and treatment. Cancer can occur in organs of the body such as the kidney or brain. These are sometimes called solid tumours. Tumours can be either benign or malignant. Benign tumours are not cancerous and do not spread to other parts of the body. However, they can keep growing and cause problems by pressing on nearby organs.

A malignant tumour is cancerous. Cells can break away from the tumour and spread to nearby tissues. They may spread further to other organs in the body through the bloodstream or lymphatic system. When the cancer cells reach a new area, they may go on dividing and form a new tumour. This is known as a secondary cancer or metastasis. Cancer can also occur in the blood cells in the bone marrow (leukaemia) or in the lymphatic system (lymphoma).



What are the most common types of childhood cancer?

There are many different types of childhood or paediatric cancers. The most common, which are grouped in this booklet according to the International Classification of Childhood Cancer (ICCC), are leukaemia and brain tumours. Almost 3 in every 4 cancers in young children are leukaemia, lymphoma or tumours of the brain and nervous system.

Common types of childhood cancers include:

Leukaemia

Leukaemia is a cancer of the bone marrow. This is the spongy material in the centre of your bones where blood cells are made. With leukaemia, the body makes too many abnormal white blood cells.

Lymphoma

Lymphoma is cancer of the lymphatic system. The lymphatic system is part of the body's immune system, which helps our body fight infection and disease. There are two main types of lymphoma: Hodgkin lymphoma (HL) and non-Hodgkin lymphoma (NHL).

Brain tumours and central nervous system tumours

There are many different forms of tumours found in the brain or in the central nervous system (CNS). Some are benign, while others are malignant. The most common types are astrocytoma, medulloblastoma and ependymoma.

Neuroblastoma

Neuroblastoma is a rare cancer that affects special nerve cells. These cells help develop the nervous system and other tissues.

Retinoblastoma

Retinoblastoma is a malignant tumour at the back of the eye. It develops in the cells of the retina, which is the part lining your eye that is sensitive to light.

Nephroblastoma

Renal tumours affect the kidneys. The most common type that affects children is called Wilm's tumour. It is also called a nephroblastoma.

Hepatic tumours

Hepatic tumours affect the liver. The most common types of malignant tumours in the liver are hepatoblastoma and hepatocellular carcinoma.

Sarcomas

Sarcomas are tumours that develop from tissue such as bone, muscle, fat or cartilage. They can occur in any part of the body and include soft tissue sarcomas, rhabdomyosarcoma and bone tumours (see below).

Malignant bone tumours

The most common malignant tumours in bones are Ewing sarcoma and osteosarcoma.

Gonadal and germ cell tumours

Germ cells are normally found in the embryo that develops into a baby in the womb. These cells in time mature into sperm or egg cells in the testicles or ovary. Some of the cells can remain in different parts of your child's body after birth and may develop into tumours. These tumours are known as germ cell tumours or embryonal tumours. Gonadal germ cell tumours start and stay in the child's reproductive organs (testicles or ovaries).

Other epithelial and melanomas

This category includes tumours in the roof of the mouth (nasopharyngeal carcinoma) and the skin (melanoma).

Langerhans cell histiocytosis (LCH)

Langerhans cells are a type of white blood cell that normally help the body fight infection. They are found in your skin and mucous membranes. In LCH, too many Langerhans cells are produced and build up in certain parts of the body where they can form tumours or damage organs.

Other and unspecified

This category includes very rare tumours that occur in children. They can be found in any part of the body. For example, cancer of the salivary gland, bowel, appendix, lung and bladder.

Survival rates

There have been huge improvements in cancer treatments for children in the past 50 years. As a result, more children than ever are surviving cancer. Some forms of cancer are now completely curable. Research is also continuing to improve treatments and reduce side-effects. Every child is different and your child's doctor will talk to you about their illness and the likely success of treatment.





Diagnosis and treatment

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Diagnosis

What does the word diagnosis mean?

Diagnosis means finding out what is wrong with your child, and if it is cancer, which type it is. Doctors will do this by assessing your child and their symptoms and by doing tests. When a child has symptoms that could be caused by cancer, usually they will be referred by their GP or local hospital to one of the following specialists:

A **paediatric oncologist** is a doctor who specialises in treating children with cancer.

A **paediatric haematologist** is a doctor who specialises in treating blood disorders in children.

A **paediatric surgeon** is a doctor who performs surgery on children.

Tests

What tests might my child need?

Various tests will be done to give the doctors more information about your child's illness. Many of these tests will be carried out in Children's Health Ireland at Crumlin, but some may be carried out elsewhere.

Your doctors will tell you which tests your child needs, depending on their diagnosis. Possible tests include:

- Biopsy
- Blood tests
- Bone marrow tests (bone marrow aspirate)
- Lumbar puncture
- X-rays
- Ultrasound scan
- CT scan
- MRI scan
- Bone scan
- PET scan
- GFR test
- Audiogram (hearing test)
- Eye exam

See pages 79-84 for an explanation of these tests. They are also explained in more detail in **Passport**.

Types of treatment

The treatment offered to your child will depend on the type of cancer they have. There are a number of treatments available. The most common include:

Surgery

This aims to remove the tumour during an operation.

Chemotherapy

This uses anti-cancer drugs to destroy cancer cells.

Radiotherapy

This uses radiation to destroy cancer cells.

Stem cell and bone marrow transplants

These involve giving high doses of chemotherapy drugs to children and then helping them recover by giving an infusion (drip) of healthy cells called stem cells. These cells can come from the child themselves (autologous) or from a donor (allogeneic).

Immunotherapy

This uses specific drugs to help children's immune systems target cancer cells.

Targeted therapy

This uses drugs to target specific proteins and genes in cancer cells.

Your child's doctor will explain which treatment, or combination of treatments, they consider suitable for your child. They will also respond to any worries or questions you might have. Before any treatment is given, consent and assent (agreement) will be sought from you and your child. Once a child reaches the age of 16, they can usually consent to their own treatment.

Side-effects of treatment

There are usually some side-effects to cancer treatment. These will depend on the type of treatment and how your child responds to it. The doctors and specialist nurses will give you specific advice about side-effects.

For example, hair loss is a possible side-effect of many chemotherapy drugs. If the hospital team expects this to happen to your child, they will advise you on ways to deal with it. Talk to them if you have any queries or concerns. Side-effects are also dealt with in *Passport*.

Complementary therapies

It is natural to want to try to help your child in any way you can. Complementary therapies can't treat or cure cancer, but can help to manage some side-effects of treatment and help your child to feel better in themselves. Some therapies, such as relaxation and gentle massage, are available in the unit. Talk to your child's consultant before using complementary therapies.

What's the difference between complementary and alternative therapies?

Complementary therapies are used **together with** standard medical treatment. Alternative therapies are used **instead of** standard medical care. Modern medical treatments are very effective at curing cancer and keeping it under control. An unproven alternative could harm your child's health, or they might miss out on a treatment that could really help them. Talk to your child's consultant if you have any questions about treatment or alternative therapies.

Email: supportline@irishcancer.ie

Children's Health Ireland (CHI), Crumlin

Children's Health Ireland (CHI) at Crumlin is the national referral centre in Ireland for children from birth to 16 years who have blood disorders and/or cancers. The hospital has a 19-bed inpatient unit called St John's Ward, which includes four transplant beds. As well as St John's Ward, there is the Haematology/Oncology Day Unit (HODU), which provides day services.

The hospital has direct links with other hospitals to provide other specific services your child may need, such as:

- **Neurosurgical services** at CHI, Temple Street for younger children and at Beaumont Hospital for older children
- **Radiotherapy services** at St Luke's Radiation Oncology Network
- **Retinoblastoma services** at CHI, Temple Street

CHI Crumlin also has links with hospitals around the country through its shared care programme. Shared care means some of your child's treatment can be given at a designated shared care centre in your local area. This can help you and your family spend as much time as possible close to home.



International links

World-class research is carried out at CHI, Crumlin. It teams up with the major international paediatric oncology groups, which helps it to stay up to date with the latest treatments. These are often available through clinical trials.

CHI, Crumlin is a member of the:

- International Society of Paediatric Oncology (SIOPe) – based in Europe
- Children's Cancer and Leukaemia Group (CCLG) – based in the UK and Ireland

Clinical trials

Clinical trials are research studies that try to find new or better ways of treating cancer or reducing side-effects. They can also help improve a person's quality of life when living with cancer. Because of clinical trials, the hospital is constantly improving and refining its treatments, and so the outcomes for children with cancer are getting much better.

Children's Cancer and Leukaemia Group (CCLG)

CCLG is a network of 20 specialist centres for diagnosing and treating children's and teenage/young adult cancers throughout the UK and Ireland. CHI, Crumlin has one of the largest centres within the group. The group supports the 1,700 children who develop cancer each year in the UK and Ireland. See page 72 for more on CCLG.



Support Line Freephone 1800 200 700

Getting to Children's Health Ireland at Crumlin



By car

From city centre

The hospital is about a 20- to 30-minute drive from Dublin City centre. Drive south onto Patrick Street and take a right onto Cork Street. Continue driving along Cork Street, onto Crumlin Road, and the hospital is at the end of Crumlin Road on the right. Sat. Nav. Co-ordinates: N 053.32633 degrees W 006.31757 degrees.

Via M50

Take Exit 9. Head to the city centre and follow the signs for R110/Long Mile Road. After passing Drimnagh Castle School, continue onto Drimnagh Road. After Ronald McDonald House, take the next left onto Cooley Road and you will come to Car Park Entrance 1 of the hospital.

By bus

Dublin Bus routes serving the hospital include:

No 18, 27, 56a, 77a, 77x, 122, 123, 150, 151. The buses operate from various points in the city centre and can change from time to time. For bus timetables and departure points, visit www.dublinbus.ie

By rail

Luas

The Red Line that serves Tallaght and Connolly Station stops at Drimnagh, which is a 10-15-minute walk to the hospital. For further information, go to www.luas.ie

Dart

Coming from the southside of the city, take the Dart (Greystones/Bray to Malahide) to Pearse Station. As you exit the station, turn right and right again onto Pearse Street. Go to the nearby bus stop and take the No 56a or 77a, which will stop outside the hospital. Journey time is about 20-25 minutes, depending on traffic.

For Dart timetables, visit www.irishrail.ie

Coming from the northside of the city, take the Dart (Malahide to Bray/Greystones) to Tara Street Station. As you exit the main entrance of the station, turn right onto George's Quay and you will find a nearby bus stop. Take the No 151, which will stop outside the hospital. Journey time is about 20-25 minutes, depending on traffic.

For Dart timetables, visit www.irishrail.ie

Train

Most large towns and cities connect to Dublin City via Heuston Station. The hospital is about a 15-minute drive from the station. Or, you can take the Luas and get off at the stop for Drimnagh. The hospital is a 10-15-minute walk from there. For further information, visit www.irishrail.ie

People you may meet



At CHI, Crumlin, your child's consultant and a multidisciplinary team of specialists (MDT) will plan the treatment they feel is best for your child's condition. This team meets regularly and includes many of the professionals you and your child may meet during your child's treatment:

Paediatric oncologists and haemato-oncologists are doctors who treat children with cancer. They are specialists in planning and giving cancer treatments, such as chemotherapy, targeted therapy and immunotherapy. Haemato-oncologists specialise in blood disorders, including leukaemia and lymphoma. They are also involved in the haematology laboratory, where blood and bone marrow samples are analysed.

Radiation oncologists are doctors that specialise in using radiotherapy to treat cancer.

Surgeons are doctors that carry out operations. They may take a sample of the cells to be examined (biopsy) and/or remove a tumour. They also may put in central lines and implantable ports. Neurosurgeons are surgeons who perform surgery on the brain and spinal cord.

Paediatric anaesthetists are doctors who can put your child to sleep and monitor them throughout surgery.

Non-consultant hospital doctors are doctors on the team who work under the consultant as trainee specialists. For example, specialist registrars, registrars and senior house officers.

Ward nurses: The clinical nurse manager (CNM) is in charge of the ward. Staff nurses and student nurses work under the CNM's direction. Nurses on the unit have specific training in working with children with cancer.

Advanced nurse practitioners (ANP) are nurses who have extensive knowledge and training and are skilled to a high level in the care of children with cancer.

Clinical nurse specialists (CNS) are specially trained nurses that provide education and information to help you care for your child at home. They can also liaise with your primary healthcare team and shared care centre.

Transplant nurse specialists are specially trained nurses who can inform you and your family about bone marrow or stem cell treatments. They are involved in organising all tests needed before and after the transplant and can support you and your family throughout the process.

Healthcare assistants are trained to give children essential care and support with day-to-day living. They can also help nurses, doctors and other healthcare professionals.

Medical social workers are trained to help you and your family with your social issues and emotional and practical needs. They can also give advice on benefits and financial matters and on supports and services available to you.

Pharmacists are responsible for supplying medicines for use in the hospital and advising doctors, nurses and parents about all aspects of their use. They are based in the hospital pharmacy and may also visit the ward and Haematology/Oncology Day Unit.

Cancer Support Specialist (CSS): The CSS provides ongoing practical and social support to children and young people and their families. The CSS is based on St John's Ward and works as part of the team, ensuring families are aware of and have access to all the support services available to them. The CSS also helps families avail of other charitable supports, accommodation and transport.

Physiotherapists help to restore wellbeing to children and adolescents after injury, pain or disability. They can assess your child and develop individual treatments to promote, maintain and restore normal development, movement, balance and posture. This is done by taking account of your child's health status and their level of development.

Occupational therapists (OTs) provide rehabilitation and ways to help your child with their everyday activities. Their services are aimed at improving the loss of any functions and managing fatigue and energy loss. Therapies include helping your child if they're at risk of developmental delay because of long and frequent hospital stays.

Pathologists are doctors who analyse tissues samples (for example, biopsies) under the microscope to diagnose illness or see how an illness is responding to treatment.

Child psychologists can support your child, adolescent or family to adjust and cope with a cancer diagnosis and the impact of treatment. They can help your family address issues that may arise in relation to your child's behaviour, how they are coping emotionally and schooling concerns. These issues can happen at any stage of treatment, at the end of treatment or after it has finished.

Radiologists are doctors who interpret X-rays and scans to help diagnose the cancer and plan your child's treatment.

Radiographers take X-rays.

Radiation therapists deliver radiotherapy treatment.

Dietitians are experts on food and nutrition. They can help your child grow and develop as normal throughout their treatment. At times, some children may be unable to eat enough to either gain or maintain their weight. If that becomes an issue for your child, the dietitian can support you on how best to manage it.



Play specialists use play as a preparation and distraction while making your child's experience of hospital as normal as possible. Play is an essential part of every child's life and supports social, emotional, intellectual and physical development.

School teachers: The Department of Education and Skills funds an education service in the hospital at both primary and secondary levels for children who are inpatients or repeat day patients. Your child may attend school in the ward classroom or teachers will go to your child's bedside. Teachers – with help from you, your child and the school – will design an education plan for your child to follow while in hospital.

Pastoral care team: The care and support of the whole person is important. The pastoral care team takes particular care of the spiritual needs of your child and family. Pastoral care is provided by chaplains or trained spiritual guides, catering to different religious and spiritual backgrounds. All families – those of different faiths and those of no faith – can receive comfort and support.

A **complementary therapist** can provide therapies such as reflexology, aromatherapy, Indian head massage and mindfulness for your child. They can help ease some of the stress and symptoms caused by a cancer diagnosis and its treatment.

Palliative care team: This is a group of specially trained doctors, nurses and other professionals who help support you, your child and your family if your child is diagnosed with a life-limiting cancer. They focus on the quality of life of your child by providing practical support, such as pain and other physical symptom management, and also emotional support. This emotional support is also available for you and your extended family.

Volunteers from CHI and Barretstown may also spend time playing with your child either in the playroom or individually. These volunteers are all carefully trained and vetted.

The **ward clerk** provides administrative and clerical support on the ward.

In your community

There are also healthcare professionals in the community that can be of help.

Family doctor (GP): The hospital will contact your GP so they are fully aware of the details of your child's illness in the early stages of diagnosis and during treatment.

Public health nurse (PHN): Your clinical nurse specialist will make contact with the public health nurse and will explain how the PHN will support you at home.

Life on the ward

The ethos or code of the unit is one of holistic, family-centred care. It aims to promote an atmosphere of respect for all creeds and cultures. Safety is a priority and smoking and alcohol are not allowed within the hospital grounds.



Layout and facilities for parents

St John's Ward has 19 single rooms, each of which has sleep facilities for one parent. Eighteen of these rooms have ensembles. Lounge and kitchen areas are available for parents, as well as shower and toilet facilities. The unit has a playroom, schoolroom, teenagers' den and a garden with an outdoor play area.

Children and their parents attend the Haematology/Oncology Day Unit (HODU) for day services. When treatment is complete, outpatient follow-up visits take place on the third floor of the Medical Tower (HOOPS – Haematology/Oncology Outpatients Services), which is located off the main hospital corridor near the entrance to the canteen.

Ward routine

On your arrival, the ward staff will familiarise you with the ward and its routines. If you have any specific requests, feel free to discuss them with the staff.

Hospital facilities

There is a shop, canteen and two coffee shops in the hospital. You will also find vending machines with sandwiches and snacks in common areas throughout the hospital. There is an ATM in the outpatient department, a chapel and a postbox, which is located beside the main reception desk.

There are internet surfboxes with printers located on the ground floor. Free wifi is available in St John's Ward and in the parents' accommodation unit. A citizens information service, provided by Citizens Information, is available outside the hospital canteen at specific times.

There are limited car-parking facilities at the hospital, with hourly and daily rates. The parents/guardians of inpatients who stay more than 10 days at a time qualify for a reduced car park rate. This is €36 for the first week and €10 per week thereafter. Please ask your child's nurse for an application form.

Parent accommodation

Most of the wards include beds or chair beds so that you can stay with your child in their room. Fold-up mattresses are also available, along with sheets and blankets. Only one parent/guardian is allowed to stay each night.

CHI Crumlin also has a parent accommodation unit that offers a small number of rooms for parents/guardians to stay. This is located on the second floor of the hospital – the stairs are located near the canteen. The accommodation consists of single and double rooms, bathrooms and showers, sitting rooms and kitchens. It also has laundry facilities.

Accommodation cannot be guaranteed. Priority is given to the parents/guardians of seriously ill children, postnatal mothers, breastfeeding mothers and those coming from outside Dublin. You should contact the Accommodation Office on (01) 409 6622 as soon as you receive an admission date for your child if you would like to stay. There is a fee of €18 for a single room and €30 for a double room. Reduced rates are available for medical card holders.



Also, Ronald McDonald House is on the hospital campus. This is accommodation aimed at families who have to travel for 2 hours or more to get to the hospital. Your child should either be a patient on the ward or be undergoing treatment as an outpatient for 5 days or more. The house has 20 ensuite bedrooms and meals are prepared for families most days. There are also laundry facilities. The house tends to get booked up very quickly and may have a waiting list. To request a room, a family member or guardian must contact Ronald McDonald House by calling (01) 456 0435 or emailing ronaldhouse@rmhc.ie.

Hospital staff can advise you on how to book the various types of accommodation or recommend nearby hotels with reduced rates for families of sick children attending the hospital.

Looking after your child

As a parent, you are encouraged to stay with your child in hospital. You are essential to your child's wellbeing and will be given all the support you need to be involved in their care. Brothers and sisters over the age of 18 can stay overnight instead of a parent.

Having tests and treatment

Most of your child's treatment will be given on St John's Ward or HODU as an infusion (drip) or injection through a Hickman line or portacath. It might also include medication taken by mouth. Some children may receive chemotherapy into a special reservoir under their scalp, or into their spinal fluid under anaesthetic in theatre.

It is better to be open with your child about a test or procedure that may hurt. For example: 'This will hurt, but only for a minute'. In this way, your child knows what to expect and is sure of your support. Your child might like to take part in the Beads of Courage programme. For every kind of test or treatment they have, they receive a coloured bead. They can collect these beads to keep track of their cancer journey and show just how brave they are. This programme is run by the play specialists in St John's Ward.

Visits from family members

Visits from the wider family and school friends can be good for your child too. They can cheer up your child, especially if they're in hospital for long periods. Always check with staff if there are any restrictions in relation to the times people can visit and how many people can visit. Also remember, it can be tiring for your child if there are too many visitors at once.

If your child is feeling unwell during or after chemotherapy, it may be best to have only one person with them at a time. Make sure your child gets all the rest they need. It may be better to encourage school friends and neighbours to visit when your child returns home and is in better form. All visitors should be well and have no signs of infection.

School and play

School is important for your child during treatment. As mentioned earlier, play is an essential part of every child's life and supports social, emotional, intellectual and physical development. See pages 49-52 for more details about school and play.

Looking after yourself

As parents, you may find it helpful to take turns being with your child in hospital. It is important to get home to other family members or just to take time for yourself. It can be a strain to be in the same surroundings all day, so you might find it helpful to leave the ward for at least one short break during the day. The nursing staff will understand this and encourage you to take regular breaks. A visit to the canteen or coffee shops is a good idea. You will meet other parents and get to know them. It will do you good to take a walk in the garden in the fresh air or to the nearby shops. A break from the ward and the hospital environment can often help to raise flagging spirits.

Complementary therapies

There are facilities for complementary therapies in the unit for both you and your child. These include aromatherapy, reflexology and Indian head massage. They can help ease some of the stress and anxiety you may be experiencing.

Expressing your feelings and worries

Talk about your feelings or worries with the nurses, medical social worker or family support worker. They are experienced in caring for children with cancer and are there to help and support you.

Email: supportline@irishcancer.ie



Parents coping with a child's cancer

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Going home after diagnosis and starting treatment

Going home after your child has been diagnosed with cancer can be very daunting for you as a parent or guardian. Remember that the hospital team will be planning for you and your child to go home as soon as your child is well enough. They will organise some of the things you will need and services to link in with. For example, the pharmacist will talk to you before your child is discharged about giving medicines at home and provide information leaflets and charts, if needed. They will also contact your local pharmacy to advise them about any medicines needed. The hospital team will also help to prepare you for what to expect during your child's treatment.

Passport contains a lot of information and guidance and will be an important resource for you at home. It also has all the contact numbers you will need when you have questions or concerns. A plan will be made for when your child needs to attend the hospital and/or the local shared care hospital for check-ups and blood tests, or treatment.

How will my child's cancer affect me?

Having a child diagnosed with cancer will affect you and the people close to you. Understandably, you will feel worried and stressed as you come to terms with the diagnosis and what it means for your child. You will no doubt worry that your child will suffer and that your family life is going to be completely disrupted. Some parents may also feel that they will lose their child.

When first told the diagnosis, you may feel numb, confused, or unable to hear or remember information about your child's diagnosis or treatment. You may also feel overwhelmed by painful and powerful emotions. These reactions are normal – remember, the doctors and nurses are there to help you at this time. There are also other people and organisations that can offer support (see pages 73-76).

Who to tell and what to say

These questions worry all parents at first. A diagnosis of cancer comes as a shock. It is normal to find it difficult to talk about to others. But each family will have their own way of dealing with the situation. Most parents find that it is best to tell close relatives and friends the truth. Their support will be invaluable and it will be a relief to talk to them. With acquaintances or colleagues, a short simple explanation is all that is needed.

Feelings and emotions

There is no right or wrong way to feel. You will probably find that your emotions go up and down a lot during the days and weeks following the diagnosis, and that your feelings change over time. You may not experience all the emotions we describe briefly here.



Shock

This is one of the most common feelings when first faced with a child's cancer diagnosis. Shock is a completely normal reaction that can cause a range of physical and emotional symptoms. In the short term, these can include lack of sleep, lack of appetite, nausea and anxiety.

Fear and denial

You may feel scared, anxious and panicky about what's going to happen and what the future holds. It can sometimes be hard to accept that children can experience serious illness.

Sadness

It is natural to feel sad or depressed at times. Every parent wants their child to be healthy, happy and carefree. Cancer and its treatment can have a big impact on you and your child's life. At times, you may have feelings of hopelessness. You may find it difficult to eat or sleep, or feel as though you have no energy for the things you need to do each day. Parents often say that they feel overwhelmed by the enormity of the situation. These painful and unpleasant feelings are sometimes unavoidable and you may have them at various times during your child's illness.

Remember, it is important to have support to help you through these times. It may help to talk to a medical social worker or specialist nurse or doctor at the hospital. You can also talk to a cancer nurse on the Irish Cancer Society's Support Line on 1800 200 700.

The Society also runs a Parent Peer-to-Peer Support programme. This connects the parents of children with cancer with trained parent volunteers who have children that have been treated for cancer in the past. This service is also available to other adult family members, such as grandparents. To be referred to a trained parent volunteer, call our Support Line on 1800 200 700 or email supportline@irishcancer.ie

Guilt

It is very common for a parent to feel guilty if their child has cancer. Some people wonder if it was something they did or didn't do that caused the cancer, or if it's a punishment for something they did in the past. Sometimes parents blame themselves for not noticing their child's symptoms quickly or feel they did not do enough. Always remember that you are not responsible for causing your child's cancer.

Anger

It is also normal to feel angry at times. You may feel angry that your child has to endure tests and treatments and that results are not available immediately. Coping with the unfamiliar world of hospitals, doctors and nurses may also be difficult. Some people may even find that they are angry with their child, as it's their illness that is causing so many problems for the family. This can be distressing but it is also normal.

Parents can feel angry at each other, especially if they have different ways of coping with their child's illness. For example, one parent might want to talk about it a lot, while the other might just want to get on with normal life as much as possible. When stressed and angry, try and respect each other's way of coping. You may also feel angry with family or friends who make thoughtless remarks or are too busy to give you support. Or you might feel frustrated with people who avoid you because they don't know what to say.

Stress

It is natural too to feel stressed as you deal with the pressure that the diagnosis and treatment can cause. Trying to balance looking after your sick child and the needs of their siblings at home can be difficult. The hospital team looking after your child will guide you towards whatever supports are in your area. Sharing your worries can be helpful.

Finding support

Family and friends

Grandparents, aunts, uncles or other close family relatives often have reactions similar to those of parents and may struggle to deal with some of the same emotions. They usually need to be given a reasonable amount of accurate information about what is happening. They may appreciate being asked to give help and support.

Emotional support

There are many people who can help you deal with any difficult feelings and emotions. You might want to talk to someone close to you, such as your partner, or a friend or family member. However, some people find it easier to talk to someone they don't know so well, such as a healthcare professional or perhaps a colleague at work. The staff at the hospital, including medical social workers and specialist nurses and doctors, can listen and talk to you too. The team may direct you to counselling services, complementary therapies and parent peer-to-peer support at your local cancer support centre. See www.cancer.ie/support

Cancer support specialist (CSS)

As well as the CSS based on St John's Ward (see page 24), there are also community-based CSSs. These provide social and emotional support to families in their homes, communities and shared care centres. Individual support is tailored to each child or young person, using a variety of activities, games, exercises, art-based mediums and discussion-based methods to develop relationships and meaningful engagement. The hospital-based CSS will refer the young person to this service.

Coping with the impact of the diagnosis

No two families are the same. The size of the family, age of children, financial circumstances and so on, can vary greatly. Each parent or couple must work out a solution to suit their own needs. Some general guidelines that might help include:

- **Work together and share the burden**

If you are part of a couple you will need to share the new burden together, not just on a practical level but on an emotional level too. You need one another and your child needs you both. If you can both be involved in accompanying your sick child to the hospital or in caring for the other children and your home, so much the better. This may not always be possible, of course, but do try to share the demands of the new situation.



- **Two heads are better than one**

It is important that you fully understand what the diagnosis and treatment mean. You will be in a state of shock at first. You may feel confused by all the new information you receive and find it hard to take it all in. If you are attending important meetings with your child's consultant, try to have your partner, a friend or family member with you.

- **Ask questions – don't be afraid**

When you have recovered from the shock of the diagnosis, you will have many questions. Many parents find it useful to write out a list of their questions at home to bring with them to the hospital. Don't be afraid to ask questions about any aspect of the diagnosis and its effect on your family. Staff will do their best to answer your questions honestly but some questions can't be answered straight away.

- **Family and friends can help**

Try not to make your sick child the centre of your world. You will lose out if you cut yourselves off from family and friends. Stick to the normal routine and family activities as far as you can to keep the whole family feeling secure. Accept any offers of help with household tasks or to look after your other children, so that both you and your partner can go to the hospital.

- **Relax – take a break**

Take a mental step back from your sick child when they need you less. Take opportunities to spend time by yourself, with your partner, family or friends and with your other children. Get a babysitter occasionally so that you can pursue your own interests or go out for a few hours. Your sick child will enjoy the company of someone outside the family.

- **Ask for help if you need it**

Sometimes, coping with a child with cancer can put a strain on a relationship. If you feel this is happening, ask for help. The medical social worker is there to help you during this difficult time.

- **Seek support from other parents**

There are opportunities to meet other people with similar fears and worries, share information and advice and support each other. Call the Irish Cancer Society Support Line on Freephone 1800 200 700 or email supportline@irishcancer.ie to find out about parent peer-to-peer support.

Practical support

GP and public health nurse

Your specialist nurse will contact your GP, local hospital and public health nurse and tell them about your child's diagnosis and treatment plan. These local support services are important, as some of your child's care might take place closer to home.

Travel costs and practical help

Looking after a sick child can cause extra expenses and difficulties. Often parents living outside the Dublin area face the added difficulties of travel and having to organise the care of their families for longer periods while away. For some, there is the added problem of living in an isolated area. Ask for help from family, friends and neighbours in coping with your new routine. They may like to help in a practical way. For example, prepare a meal, do a school run or help with laundry. The medical social worker will advise you about benefits to which you may be entitled and other financial supports, such as grants. See page 59 for more about financial matters.



Advice for one-parent families

Being a lone parent of a child with a life-threatening illness can be especially difficult. You may have less emotional or practical support if you are a lone parent. You may also have difficulties juggling work commitments and caring for your sick child. Asking for and accepting help will help you and your family.

Try to find people to talk with and to help with your family's day-to-day needs. The medical social worker can be a great support at this time. Your family, friends, neighbours or religious leader may be able to help too.

Employers may find or arrange special ways for you to do your job and still be with your child. Try to be as clear and specific as possible about your needs and what is most important to you. Your other children need time with you too, but you should look after your own needs as well.

Seeking information

You may want to find out as much as possible about the cancer and its treatment. There is a great deal of information on the internet, however it may be hard to understand or it may be incorrect. Also, the information may not apply to your child's situation or their particular cancer type. Talk to the doctors and nurses about where to look for reliable information. The best advice is to use a website by a recognised organisation such as the Irish Cancer Society or the Children's Cancer and Leukaemia Group (CCLG). The Society provides lots of information online at: www.cancer.ie/children

Some UK websites such as Macmillan Cancer Support and Cancer Research UK also have good information, but remember that treatments and supports may not be the same in the UK.

You can also talk to an Irish Cancer Society cancer nurse on 1800 200 700 or visit a Daffodil Centre. See pages 73-76 for a list of support organisations and websites.

Looking after yourself

Remember to take care of your own needs. Your health and wellbeing are important at this stressful time. Eating and sleeping well, exercising and taking regular breaks will help you cope and care for your child. Talking to a friend or loved one can be very helpful. Have the usual check-ups and let your family doctor know if you feel run down or you're finding it hard to cope emotionally.

Socialising

At this time, you might avoid seeing friends and taking part in social activities. This is very understandable.

However, it can help to keep up with your usual interests as much as possible. Having a break and being distracted from the cancer and its treatment will do everyone good. Some of your friends may not know what to say, so it may be up to you to bring up the subject of your child's illness. Others may surprise you with their sympathy and understanding.



Returning to work

It is sometimes very difficult for families to know how to manage work and how and when to return to work. Don't rush into any decisions but tell your employers about your situation and see what flexible working arrangements they can offer you. If you feel unable to work, then it might be a good idea to make an appointment to see your GP.

Children coping with cancer

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Your child's feelings

When a child is diagnosed with cancer, it obviously has a big effect on them. They may be very frightened along with feeling unwell, while having to cope with the side-effects of treatment. They may find it hard to be away from home, family and friends.

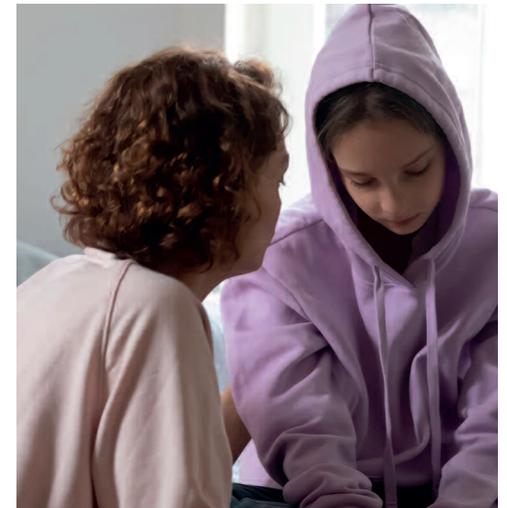
Understandably, this can have an effect on their behaviour.

Keeping normal discipline during this time is reassuring for your child and can help them feel more secure. Treatment may cause changes in their appearance, such as weight loss or gain, or hair loss. These changes can affect their confidence, especially for older children and teenagers.

Talking to your child

One of the hardest parts of caring for a child with cancer is knowing what to say and how much information to give them. Answering questions honestly is best. Some children may not ask questions, but this does not mean they do not want to know what is happening.

They may be frightened and uncertain of many things. Some children may even wonder if they have done something wrong and if they caused the cancer. You can ask the doctors, nurses and medical social workers for guidance on how to talk to your child. There are also booklets available from CCLG and Young Lives vs Cancer that can help you explain the illness and treatment. See page 78 for more details.





Here are some questions that parents commonly ask after a cancer diagnosis:

Should I tell my child that they have cancer?

Yes, if your child is old enough to understand. It is better to be truthful with them so they trust you and the hospital team. If you explain the basic facts of the disease, your child will realise that the treatment is needed. Even children who are quite young can understand about 'good cells' and 'bad cells' in their body. They can understand that the treatment will kill the 'bad cells' and stop them from becoming very ill.

Your medical social worker can provide you with children's books about cancer and its treatment. These can help your child to understand their illness at their own level. Reassure your child that nothing they or anyone else said, did or thought caused their cancer.

My child is too young to understand why he needs treatment. He does not want to come to the hospital. How can I handle the situation?

This is a very understandable challenge. A small child will naturally object to having a treatment that they find needless and unpleasant. Loving firmness is the best approach here. Your child must have the treatment, so avoid getting involved in long arguments. Instead, be firm, very encouraging and loving.

Bring all the moral support you can to the hospital in the form of a favourite teddy, soother, prized blanket or other possession. Talk to the play specialist for more ideas and support.

I feel so sorry for my child. Should I let them have what they want? I want them to be happy.

The best gift you can give a seriously ill child is a normal, predictable environment and a loving family. In general, children feel more secure when the normal home rules continue to apply. Many parents find it helpful to ask family, friends and neighbours not to give too many gifts to their child and not to forget brothers and sisters when they're giving gifts and attention.

I am afraid to let my child go out to play. Suppose they get hurt?

If your child has been given permission from the hospital to mix with other children, then encourage them to do so. They need the company of children their own age. Your child will benefit from the give-and-take of social contact and the feeling that they are like other children. Play can greatly boost a sick child's morale and self-esteem.

You might like to sign them up for a residential camp, such as Barretstown. This is a specially designed camp for children with serious illnesses and their families, based in Ballymore Eustace in County Kildare. It offers a range of adventurous and challenging activities, supported behind the scenes by health professionals. This is called therapeutic recreation. All of its programmes are free of charge. Ask your child's specialist nurse, medical social worker or the Barretstown outreach team for more details.

My teenage daughter undergoing treatment thinks her friends are avoiding her. Is there any particular support for teenagers?

Teenagers diagnosed with cancer face particular difficulties and stresses. They long to be independent and make their own way in the world, but at the same time they are becoming more dependent due to their illness. Cancer can affect friendships too. Some relationships may grow stronger, while others may fade. It can help to understand how friends feel and for your child to learn how to tell friends how they feel.

CanTeen is a nationwide teenage cancer support group set up in 1990. It aims to provide support, enjoyment, information and encouragement for teenagers who have or have had cancer. It also welcomes brothers, sisters and friends. CanTeen organises meetings, fun activities and weekends away. It provides an opportunity for teenagers to share their feelings and experiences in a supportive environment. Visit the website www.canteen.ie for more information.



Dealing with school

Children with cancer often have gaps in their education. This can be due to prolonged periods spent in hospital, the side-effects of treatment, or generally not feeling well enough to take part fully in school life. The teaching staff at the hospital will contact your child's teachers to make sure they can continue their schooling whenever they feel well enough. Children can even take exams in hospital, if needed.

As your child's health improves and when treatment allows, going back to school is a very good idea. For many children, school is a refuge from the world of hospitals and tests – a place for fun, friends and learning. Going back to school can be a sign that life is returning to normal. But some children, especially teenagers, may have some worries about going back to school. This may be because of temporary or permanent changes in their appearance. Or they may worry that they will have missed a lot of schoolwork, or that being away will have affected their relationships with their friends.

Barretstown runs an outreach School Education Programme. When children with cancer return to school, they may look different as a result of the side-effects of their treatment. This needs to be explained to their classmates to help them understand what the young person is going through and how to support them. This free programme takes a fun and interactive approach to explain what cancer is and reduce the likelihood of bullying, exclusion, confusion or anxiety. More information is available on the Barretstown website: www.barretstown.org

For school teachers, the Irish Cancer Society has a '**Cancer in the classroom**' section on its website: www.cancer.ie. This includes a series of videos covering topics such as establishing open communication and monitoring the child's behaviour.

CCLG also has a helpful book called *Welcome Back! A Guide for Teachers Helping Children and Young People Returning to School after a Diagnosis of Cancer*. This can be downloaded from the CCLG website: www.cclg.org.uk



Keeping teachers informed

Let the school know how your child is doing.

As soon as your child is diagnosed, contact the school principal to tell them what is happening. It can help to let the school know about the plans for treatment. Your child should be involved, at any stage of treatment, in letting the teacher know what information they would like shared with their classmates.

Preschool children

Many children diagnosed with cancer are very young and have not yet started school. It may be useful for you to talk to your specialist nurse or medical social worker about playschool and discuss any specific queries you might have.

Effects on brothers and sisters

The brothers and sisters of a child with cancer might have many similar feelings and emotions as you. If you have to spend a lot of time in the hospital with your child, your other children may need to be cared for by family members or friends. They may have to spend a lot of time away from you or find their daily routine keeps changing. As well as worrying about their brother or sister's health, they may also resent all the attention they are getting. This can make them feel very left out and angry. They may even worry that they are also going to get ill.

The needs of siblings can sometimes be overlooked, particularly in the early months when you may spend most of your time caring for your sick child in hospital or at home. Many will keep their feelings bottled up to avoid worrying their parents. Often, however, they may show how they feel when at school. They may:

- Withdraw and become very quiet
- Become disruptive in the classroom
- Cry easily
- Become frustrated and have outbursts of anger
- Fall behind in classwork
- Get lower marks than usual
- Start missing school
- Become rebellious towards teachers
- Have arguments and fights with friends and other children in their class

It will help to let your children's principal(s) know that their brother or sister has been diagnosed with cancer. Remember, you can ask for the school's help and support for your children. The teachers will understand that feelings may be expressed through behaviour at school, once they are aware of the stresses facing your family.

Helping brothers and sisters

The whole family will be more likely to understand and deal with the new situation if you create an open atmosphere. Depending on their ages, the children will understand to varying degrees what is going on. Giving them small amounts of information at the beginning is useful. You can then give more information if you feel they are ready. Explain that it is normal for them to experience a range of emotions and that they have your loving support.

Watch out for changes in their behaviour as they may not openly speak about their feelings. Encourage them to express these new feelings. Doing a household chore together or going for a walk can create an opportunity for them to talk to you.

Try to give each of your children some individual attention. Listen to them and reassure them of your love even though it must seem to them that their sick sibling is taking up all your energy. Even 10 minutes at the end of the day can make a big difference. If your child with cancer is having some special attention – for example, having their favourite food – do the same for the other children in the family so they don't feel left out.

Include siblings in the housework and shopping where possible and think up ways of making things easier or more cheerful for everyone.



They will rise to the challenge when they feel a part of the situation. If a sibling is obviously having difficulty dealing with the situation, talk about it with staff at the hospital, such as the specialist nurses or the medical social worker.

The Irish Cancer Society has a useful booklet called *Supporting brothers and sisters of a child with cancer*. This has practical information for parents and other adults who are caring for siblings of a child with cancer. Contact the Support Line on 1800 200 700 for a copy, or download it from www.cancer.ie

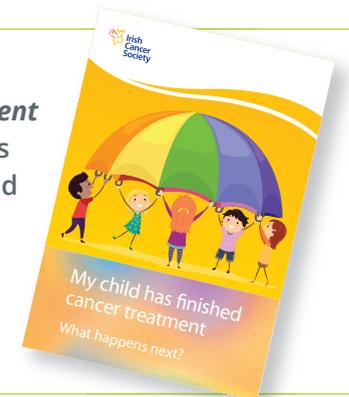
After treatment and follow-up

It is important for you and your child to attend outpatient clinics when their treatment is over. This is called follow-up. The doctors will want to check that everything is well and that your child does not have any long-term problems after their cancer treatment. This will be discussed with you at the time.

Adjusting to life after treatment

Finishing treatment is a long-awaited day for you and your child, but it can still be an anxious time. It is often only at this stage that the full enormity of what has happened really hits you. Fears that your child's cancer might return are very common. You may also find yourself missing all the support from the staff on the ward and contact with the other parents. Just remember that this is all normal. It takes time to trust that all is well again.

The Irish Cancer Society booklet *My child has finished cancer treatment* helps answer some of the questions and concerns that arise when a child finishes their cancer treatment. Contact the Support Line on 1800 200 700 for a copy, or download it from www.cancer.ie



Support Line Freephone 1800 200 700



Support resources

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Health cover and financial matters

One of the first worries many parents have is how to pay for all the extra costs their child's cancer diagnosis brings. Health cover falls into two groups – cover for medical card-holders and cover for all other groups. We will break this section up under the following headings:

- Hospital cover
- Outpatient cover
- Medical card
- GP visit card
- Long-Term Illness Scheme
- Drug Payments Scheme (DPS)
- Private health insurance
- Benefits and allowances

At the end of this section, there are also some useful telephone numbers and addresses for further help. Remember, rates and charges can change each year in the Budget. The figures we quote are correct at the time of going to print (end of 2023).



Hospital cover

Everyone, including children, is entitled to free hospital inpatient services in a public ward in all public hospitals. (Public inpatient charges of €80 a night, up to a limit of €800 in 1 year, were abolished for children under the age of 16 in September 2022 and for adults in April 2023.) Rates can apply for semiprivate or private care.

Outpatient cover

If you bring your child to the outpatients or emergency department of a public hospital without being referred by a GP, you may be charged €100. There is no charge if you have a medical card or are admitted to hospital after attending the emergency department.

Medical card

Children under 18 diagnosed with cancer are entitled to a medical card for 5 years following diagnosis. Any child under the age of 18 who had a diagnosis in the previous 5 years is also entitled to a medical card for 5 years. A medical card usually allows your child to have free GP services, prescribed medicines, inpatient public hospital services as well as outpatient services and medical aids and equipment (appliances). You may have to pay a prescription charge, currently €1.50 per item, up to a limit of €15 per family per month.

To apply for a medical card on behalf of your child, download an application form and apply online (www.medicalcard.ie) or at your local health centre. LoCall 0818 22 44 78.

If your child still has considerable health expenses after the 5 years, you can apply for another medical card. You may be means-tested to qualify for a second card. Financial guidelines are set out each year and are available from your local HSE office or from its website: www.hse.ie

If your means are above but close to the guidelines, you should apply for a card anyway. A card may be granted in some situations – for example, if you have a large amount of medical costs. This is known as a discretionary medical card and will depend on your

financial circumstances and how long your child's treatment is expected to last. The burden of their illness will also be taken into account and the card will be reviewed periodically. If your child has a terminal illness, they will receive a permanent medical card that will not be reviewed.



GP visit card for children

While all children with cancer are entitled to a medical card for 5 years, it should be noted that all children under the age of 8 living in Ireland can get a GP visit card. If you have other children in this age group, this may help to reduce other medical costs for the family.

The GP visit card covers:

- Free GP visits
- Assessments at ages 2 and 5
- Out-of-hours urgent GP care
- Care for children with asthma

The card does not cover the cost of medications and medical appliances.

You can register online for the scheme at www.hse.ie or by post. You can order an application form in the post by calling 0818 22 44 78.

Completed forms should be sent to:

National Medical Card Unit – Under 8s GP visit cards

PO Box 12629

Dublin 11

Long-Term Illness Scheme

There is a list of medical conditions that qualify for the Long-Term Illness Scheme. Acute leukaemia is one of these conditions. It is important to note that cancer in general is not covered by the scheme. Under this scheme, run by the HSE, your child can get free medicines, and medical and surgical appliances for the treatment of their condition.

The scheme does not depend on your income or other circumstances and is separate from the medical card and GP visit card schemes. If your child qualifies, you will get a long-term illness book. This book lists the medicines for the treatment of your child's condition. They will receive these medicines free of charge through your local pharmacist. You must pay for other medicines not related to your child's condition. You can get an application form from your GP, local health centre or by calling 0818 22 44 78. Completed applications should be posted to:

Long-Term Illness Scheme

Client Registration Unit

PO Box 12962

Dublin 11

Drugs Payment Scheme

Under the Drugs Payment Scheme (DPS), individuals and families, including spouses and dependent children, pay a limit of €80 each month to cover the cost of prescribed drugs, medicines and appliances. To apply, contact your local HSE office or local pharmacy. You can also apply online on the HSE website: www.hse.ie

Private health insurance

Private health insurance pays for private care in hospital or from various specialists in hospitals or in their practices. There are a number of private health insurers in Ireland. They provide cover for day or inpatient treatment and hospital outpatient treatment. Before attending hospital, check the level of cover provided by your insurer, both for inpatient and outpatient services. If you have private insurance, your child's tests might not be carried out as quickly as you would like. This is because your health insurer has to approve some tests in advance. For example, PET scans. Sometimes it might take 24-48 hours to get approval from your health insurer.



Benefits and allowances

You, or a family member, may qualify for a number of benefits and allowances – for example, the Domiciliary Care Allowance. The medical social worker will let you know what you are entitled to. You can also look at the **Benefits and Entitlements for Families** page on our website www.cancer.ie

Application forms for benefits are available from local social welfare offices or the Intreo Office, Government Buildings, Ballinalee Road, Longford. Tel: 0818 40 50 60. You can also download the forms from websites such as www.welfare.ie or www.citizensinformation.ie

Domiciliary Care Allowance

This is a monthly payment to the carer of a child under 16 with a serious illness or disability. The illness or disability must be such that your child needs care and attention and/or supervision over and above that given to another child of the same age. To apply, fill in an application form from your local social welfare office or Citizens Information Centre.

Travel to hospital

If it is costing you a lot to travel to and from the hospital, discuss it with your medical social worker at the hospital. Limited help may also be available from your local Department of Employment Affairs and Social Protection representative (formerly community welfare officer).

The Irish Cancer Society CAYA (Children, Adolescents and Young Adults) Volunteer Driver Service is a free service available to patients under the age of 18 travelling from within the counties of Dublin, Meath, Kildare and Wicklow to CHI Crumlin or St Luke's Hospital for chemotherapy or radiotherapy treatments. Volunteer drivers bring you and your child to hospital appointments. For more on this service, see page 69.

Tax relief for medical expenses

If you pay medical expenses that are not covered by the State or by private health insurance, you can claim tax relief on some of those expenses. For tax purposes, medical expenses are allowed for mileage to and from the hospital. Phone costs, overnight accommodation and hygiene products all directly connected to your child's treatment are also included. Remember to keep all receipts from doctors, pharmacies, hospitals, travel, accommodation, etc. To apply or to find out more, see the Revenue website: www.revenue.ie.

Further information

For advice about health cover and benefits, talk to the medical social worker. They can give you advice and help you to apply for benefits. Every situation is different. The help that is available can depend on your income, your child's illness, their age and the distance you have to travel. There are many other benefits and entitlements that may be relevant to you and your child. Always have your PPS number to hand when you are enquiring about entitlements and benefits. The most direct way to check eligibility is to contact:

- The medical social worker in your child's hospital
- Department of Employment Affairs and Social Protection – Tel: 0818 662 244 or ask to speak to a DSP representative at your local health centre or DSP office

If you have queries about health and social services, contact the HSE office in your area or use HSE Live: Callsave 1800 700 700, email: hselive@hse.ie or visit the website: www.hse.ie

Information is also available from your local Citizens Information Centre. A list of these centres is available from:

Citizens Information:

Tel: 0818 07 4000

Email: information@citizensinformation.ie

Website: www.citizensinformation.ie

If you have money problems

A diagnosis of cancer can sometimes bring the added burden of financial worries. You may find that you have a lot more expenses, such as medication, travel, food, heating, laundry, clothing and childcare costs. If you have had to take time off work to care for your child, this may cause even more stress and affect your income.

If you are finding it hard to cope financially, contact your medical social worker in the hospital or your local health centre for advice. The Irish Cancer Society can also give some help towards travel costs and other expenses in certain cases. See pages 69-70 for more details of our Travel2Care fund, CAYA Volunteer Driver Service and Children's Fund.

If you are getting into debt or you are in debt, the Money Advice and Budgeting Service (MABS) can help you. MABS can look at your situation, work out your budget, help you to deal with your debts and manage your payments. The service is free and confidential. Call the MABS Helpline on 0818 07 2000 for information.

You can also speak to a nurse on our Support Line (1800 200 700) or visit a Daffodil Centre for advice on supports that may be available to you.

More information

Go to www.cancer.ie and see our **Benefits and entitlements for families** page. This explains benefits and allowances that you or your family may qualify for.

Email: supportline@irishcancer.ie

Irish Cancer Society services

Our Cancer Support Department provides a range of cancer support services for people with cancer at home and in hospital, including:

- **Support Line**
- **Daffodil Centres**
- **CAYA Support**
- **Peer Support**
- **Support in your area**
- **Patient travel and financial support services**
- **Night nursing**
- **Publications and website information**

Support Line 1800 200 700

Call our Support Line and speak to one of our cancer nurses for confidential advice, support and information. In relation to children with cancer, the nurse can offer advice about supports that are available. The Support Line is open Monday to Friday, 9am to 5pm. Or email us on supportline@irishcancer.ie or visit our online community at www.cancer.ie



Support Line Freephone 1800 200 700

Daffodil Centres

There are 13 Daffodil Centres located in 13 adult hospitals nationwide. These centres are staffed by cancer nurses and trained volunteers who provide confidential advice, support and information to anyone concerned about or affected by cancer. Some young people may have to attend hospitals with Daffodil Centres for some of their services. They and their families are welcome to use the Daffodil Centres.

Who can use the Daffodil Centres?

Daffodil Centres are open to everyone – you don't need an appointment. Just call in if you want to talk or need information on any aspect of cancer including:

- Cancer treatments and side-effects
- Emotional support
- Practical entitlements and services
- Living with and beyond cancer



CAYA Support

The Irish Cancer Society's CAYA (Child, Adolescent and Young Adult) Cancer Nurse Coordinator is based in CHI Crumlin one day a week, to offer support and information to families.

Peer Support

We have trained parent peer supporters available to provide emotional and practical support to you while your child is going through or has finished treatment. Call our Support Line on Freephone 1800 200 700 for more information.

Patient travel and financial support services

We provide practical and financial support for patients in need who are undergoing cancer treatments. There are two services available to children through the Society:

- **Travel2Care** is a fund made available by the National Cancer Control Programme (NCCP), for patients who are having difficulty getting to and from their treatments while attending one of the national centres of excellence. The medical social worker in your child's hospital will apply on behalf of your family, if eligible.
- The **CAYA (Children, Adolescents and Young Adults) Volunteer Driver Service** is a free transport service available to patients under the age of 18 travelling from within the counties of Dublin, Meath, Kildare and Wicklow to CHI Crumlin and St Luke's Hospital for chemotherapy or radiotherapy treatment. The Irish Cancer Society is hoping to expand this service to other hospitals and counties in 2024 and 2025.

To access this service, the patient must be referred by a member of their healthcare team at CHI Crumlin. The patient must be accompanied by a parent/guardian over the age of 18 on all drives. For more information on this service, contact the Irish Cancer Society by email at childrenstransport@irishcancer.ie or by phone at (01) 231 0522

- Our **Children's Fund** offers financial support to the parents of children diagnosed with cancer. This is to help them with the unexpected expenses that a diagnosis brings, such as travel expenses to cancer treatment appointments, heating bills, childcare costs and home help.

This is a one-off grant of €3,000. It is not means tested. To qualify for the Children's Fund, the child:

- Must be under the age of 18
- Must have been diagnosed with cancer and currently be receiving treatment
- Must live permanently in Ireland

More information on this is available from the medical social worker in your child's hospital and on the Irish Cancer Society website: www.cancer.ie

Irish Cancer Society Night Nursing

We provide end-of-life care for cancer patients, including children in most areas, in their own home. Check with your palliative care team if this service is available in your area. Our service allows patients to remain at home for the last days of their lives surrounded by their families and loved ones. This is the only service of its kind in the Republic, providing palliative nursing care at night to cancer patients.



Publications and website information

We provide information on a range of topics including cancer types, treatments and side-effects, coping with cancer, children and cancer, and financial concerns. Visit our website www.cancer.ie or call our Support Line for free copies of our publications.



Local cancer support services

The Irish Cancer Society works with cancer support groups and centres across the country to ensure people affected by cancer have access to confidential support, including professional counselling. This includes parents of children diagnosed with cancer.

As a parent of a child with cancer you may like to avail of a variety of services including complementary therapies or peer support at your local cancer support centre.

Cancer support services usually have a drop-in service where you can call in for a cup of tea and find out what's available.

You can call our Support Line 1800 200 700 to find your nearest cancer support centre. Or see our online directory at: www.cancer.ie/local-support

Children's Cancer and Leukaemia Group

CCLG is a leading children's cancer charity and the UK and Ireland's professional association for those involved in the treatment and care of children with cancer.

CCLG brings together childhood cancer professionals to ensure all children receive the best possible treatment and care. It funds and supports research into childhood cancers and helps young patients and their families with their high-quality information resources.

Publications

CCLG produces an extensive range of accredited information resources for families. See the website www.cclg.org.uk for a full list or to download publications. Its *Contact* magazine is a free quarterly magazine featuring information articles and personal stories.

Principal treatment centres

CCLG's principal treatment centres work together to make sure families across the UK and Ireland have access to the best possible treatment and care.



Useful organisations and websites

Irish Cancer Society

Tel: 01 231 0500
Support Line Freephone:
1800 200 700
Email: supportline@irishcancer.ie
Website: www.cancer.ie

Childhood Cancer Ireland

A registered charity founded by and led by parents of children with cancer and survivors. It raises awareness about childhood cancer, advocates for improved services and funds vital supports for affected families.

Email: info@childhoodcancer.ie
Website: www.childhoodcancer.ie

Citizens Information

Statutory body provides comprehensive information on public services and on the entitlements of citizens in Ireland.

Tel: 0818 07 4000
Website: www.citizensinformation.ie

Money Advice and Budgeting Service (MABS)

This is a free and confidential service for people who are having problems with money management and debt.

Helpline: 0818 07 2000
Email: helpline@mabs.ie
Website: www.mabs.ie

The Little Princess Trust

A UK charity that funds real hair wigs for children in the UK and Ireland.

Website: www.littleprincesses.org.uk

Help and support in Republic of Ireland

Go to www.cancer.ie/local-support for the most up-to-date information on support in your community for parents and families.

Cancer Fund for Children

A registered charity in the Republic and Northern Ireland that provides support to families. Its cancer support specialists (CSS) work in CHI Crumlin and the community, providing practical and social support to families. It also provides a purpose-built therapeutic centre offering short stays to families impacted by cancer. Daisy Lodge is based in Co Down and there are plans to build a second lodge in Mayo.

Tel: 01 562 1580
Website:
www.cancerfundforchildren.com

Aoibheann's Pink Tie

A registered charity that provides practical assistance and support for families in need who have a child with cancer. It takes referrals through St John's Ward at Children's Health Ireland at Crumlin.

Tel: 01 240 1332
Website: www.aoibheannspinktie.ie

Barretstown

A specially designed camp for children with serious illnesses and their families.

Tel: 045 864 115

Email: info@barretstown.org

Website: www.barretstown.org

Bubblegum Club

A registered not-for-profit organisation that provides outings for children who have a life-threatening or long-term illness, or are disadvantaged in some other way.

Tel: 086 262 8888

Email: info@bubblegumclub.ie

Website: www.bubblegumclub.weebly.com

BUMBLEance

A nationwide professional medical transport service for long-term sick and seriously disabled children. It transports children in a fun environment from home to their treatment centres.

Tel: 083 00 44 444

Email: info@bumbleance.com

Website: www.bumbleance.com

CanTeen Ireland

A nationwide support group for young people aged between 12 and 25 who have or had cancer, and also for their siblings and friends.

Tel: 01 872 2012

Email: info@canteen.ie

Website: www.canteen.ie

Children in Hospital Ireland

An organisation that works directly with children in hospitals to help them cope with illness and being in hospital. It also provides ongoing support to their families.

Tel: 01 290 3510

Email: info@childreninhospital.ie

Website: www.childreninhospital.ie

Children's Leukaemia Association

An association that supports and assists families of children with leukaemia in the Munster region.

Tel: 021 494 9801

Email: info@cla.ie

Website: www.cla.ie

Cliona's Foundation

A registered charity that provides financial help for hidden costs in caring for critically ill children in Ireland.

Tel: 061 331 333

Email: info@clionas.ie

Website: www.clionas.ie

Hand in Hand

A national support service that provides practical support for families of children with cancer.

Tel: 087 660 0103

Email: support@handinhand.ie

Website: www.handinhandcharity.ie

Julie Wren Trust

A trust that provides complementary therapies for children with cancer at Children's Health Ireland at Crumlin. It also provides funding for palliative care for children at home or in hospital.

Tel: 01 428 2792

Website: www.childrenshealth.ie/support-the-children/what-your-support-does/julie-wren/

Make-A-Wish Ireland

This organisation grants the wishes of children aged between 3 and 17 living with life-threatening medical conditions to bring hope, strength and joy.

It is an affiliate of the International Make-A-Wish family.

Tel: 01 205 2007

Email: info@makeawish.ie

Website: www.makeawish.ie

Ronald McDonald House

An international charity that provides accommodation in a caring and supportive environment for families whose children are seriously ill in hospital or undergoing treatment at Children's Health Ireland at Crumlin.

Tel: 01 456 0435

Email: ronaldhouse@rmhc.ie

Website: www.rmhc.ie

Useful websites

Children's Oncology Group (COG)

Based in the US, the world's largest organisation for childhood and adolescent cancer research.

www.childrensoncologygroup.org

Jigsaw

An Irish charity that focuses on supporting the mental health needs of young people aged 12-25.

www.jigsaw.ie

Reachout.com

This is an anonymous and confidential place where young people can talk about their health and mental wellbeing.

<http://ie.reachout.com>

SteppingUP.ie

Irish website with information and support for young people with long-term illnesses moving from child to adult health services.

<http://steppingup.ie>

Stupid Cancer

Global support community for adolescents and young adults with cancer.

<http://stupidcancer.org>

Teenage Cancer Trust UK

Cancer information and support forum for teenagers with cancer.

www.teenagecancertrust.org

Useful contacts outside Republic of Ireland

The Brain Tumour Charity

UK charity funding research and raising awareness of brain tumours.

Tel: 0044 808 800 0004

Website:

www.thebraintumourcharity.org

Cancer Focus Northern Ireland

Supports local cancer patients, their families and carers.

Tel: 028 9066 3281

Email: hello@cancerfocusni.org

Website: www.cancerfocusni.org

Cancer Research UK

A charity that conducts and funds research on cancer. It also provides education and information about cancer.

Email:

supporter.services@cancer.org.uk

Website: www.cancerhelp.org.uk

Children's Cancer and Leukaemia Group (CCLG)

For more information, see page 72.

Tel: 0044 333 050 7654

Email: info@cclg.org.uk

Website: www.cclg.org.uk

Lymphoma Action (UK)

A UK charity that provides in-depth information on lymphoma.

Helpline: 0044 808 808 5555

Email:

enquiries@lymphoma-action.org.uk

Website: lymphoma-action.org.uk

Macmillan Cancer Support

A UK charity that provides specialist healthcare, information and financial support to people affected by cancer.

Tel: 0044 808 808 0000

Website: www.macmillan.org.uk

National Cancer Institute (US)

The US government's main agency for cancer research and training.

Website: www.cancer.gov

Neuroblastoma UK

A UK charity dedicated to finding a cure for neuroblastoma.

Tel: 0044 20 3096 7890

Email: hello@neuroblastoma.org.uk

Website:

<https://www.neuroblastoma.org.uk>

Sarcoma UK

UK charity that funds vital research and offers support for anyone affected by sarcoma.

Email: info@sarcoma.org.uk

Website: www.sarcoma.org.uk

Young Lives vs Cancer (previously known as CLIC Sargent)

UK children's charity that publishes a wide range of books, including storybooks.

Helpline: 0044 300 330 0803

Email:

getsupport@younglivesvscancer.org.uk

Website: younglivesvscancer.org.uk

Helpful publications

There are a number of useful publications available from various organisations. These are aimed at parents, guardians, carers, family members, friends and schools.

Irish Cancer Society

Precious Times: A handbook on palliative care for parents of children with cancer

Brain and spinal cord tumours in children: A guide for parents and family

Supporting brothers and sisters of a child with cancer: A practical information guide. This is for parents and other adults who are caring for the siblings of a child with cancer

My child has finished cancer treatment: What happens next? This is a guide that aims to help parents and carers to adjust to normal life after their child or teenager has finished treatment for cancer

When your child's cancer comes back – or if it does not respond to treatment: This is information for parents and families of a child or young person with relapsed or refractory (does not respond to treatment) cancer

Guide for families of children receiving proton beam therapy:

This leaflet will tell you all you need to know if your child is going to have proton beam therapy abroad. (Available to download only)

Children's Health Ireland

Chemotherapy: What is it? A colouring book for children who are receiving chemotherapy

Passport: Information for parents

CCLG

The CCLG has a wide range of booklets and factsheets on, for example, types of children's cancers, diagnosis, treatments and managing symptoms and advice for family members.

Examples include:

Diagnosis

Children and Young People with Cancer: A Parent's Guide (2017)

Managing family life and cancer (2016)

Taking part in clinical trials (2021)

Everyday life

Anna loses her hair: A children's guide to hair loss as a result of cancer treatment (2022)

After treatment finishes

Living beyond cancer (2022)

All booklets can be downloaded from the CCLG website at www.cclg.org.uk/publications.

Young Lives vs Cancer

This is a UK cancer charity for children and young people and their families. It also publishes a wide range of books and online information for children, parents and families.

Visit www.younglivesvscancer.org.uk to view or download publications. Examples include:

For parents and guardians

My child has cancer. What now? A practical guide for parents and carers (2023)

For teenagers and young adults

Boredom busters when you're staying in hospital

For children

Joe has leukaemia (2017)

Mary has a brain tumour (2017)

Tom has lymphoma (2018)

Medical terms explained

Doctors may use words that you don't understand.

If you don't understand the words a doctor or nurse uses at any time, don't feel embarrassed to ask them to explain them to you.

Acute Occurring suddenly over a short period of time.

Alopecia Hair loss.

Anaemia A reduced number of red blood cells.

Anaesthetic Drugs that put your child to sleep (general anaesthetic) or that numb a part of their body (local anaesthetic).

Antibodies Proteins created by the immune system when exposed to toxins or other foreign substances such as viruses and bacteria. Antibodies recognise and latch onto the foreign substance, removing them from the body.

Audiogram A chart that shows the results of a hearing test.

Benign Not cancer.

Biopsy A small sample of tissue taken from the body to make a diagnosis.

Blood tests Doctors often examine blood samples to help them to diagnose your child's illness. Blood tests may be done when your child is diagnosed, during treatment and afterwards at follow-up appointments.

Blood count A blood test to check the number of different cells in the blood. Sometimes it is called a full blood count or FBC.

Bone marrow The spongy material in the centre of large bones in the body which makes blood cells.

Bone marrow aspirate/biopsy A test that takes a sample of bone marrow or bone using a needle. When a sample of semi-liquid bone marrow cells is taken, it is called an aspirate. When a piece of bone or solid marrow is taken, this is called a trephine biopsy.

Bone scan A test that can show if cancer is present in bones using a radioactive dye.

Cannula A short plastic tube put into a vein to deliver medication, fluids or a transfusion.

Cardio- To do with the heart.

Catheter A thin, flexible tube used to give fluid into the body or to drain fluid from the body. For example, a urinary catheter or a central line, such as a Hickman line.

Cerebrospinal fluid (CSF) Fluid made in the brain that surrounds the brain and spinal cord.

Chemotherapy Drug treatment that kills cancer cells.

Chromosome Structure in the nucleus of the cell that contains the genetic make-up of the cell.

Chronic A condition that lasts for a long time.

CNS Central nervous system. It refers to the brain and spinal cord.

Congenital Any condition existing at birth.

CT (CAT) scan This special X-ray gives a detailed picture of the tissues inside your body. During the scan, your child will lie on a table which passes through a doughnut-shaped machine. The scan is painless.

Cyto- To do with cells.

Cytogenetics The study of chromosomes in cells.

Dysfunctional Something not working properly.

ECG (Electrocardiogram) This tests the electrical activity of the heart muscle. Electrical sensors are placed on your child's chest for the test.

ECHO (Echocardiogram) This is an ultrasound scan of the heart. It checks how well the heart is working.

EEG (Electroencephalogram) This tests the electrical activity of the brain. It is not painful but will involve electrical sensors being attached to your child's head.

Electrolytes The minerals and salts in the body. For example, sodium, potassium and calcium.

Endocrine To do with hormones.

Excision Cutting out.

GCSF (granulocyte colony stimulating factor) This is a type of protein called a growth factor. It boosts the bone marrow to make more white blood cells, usually neutrophils, which are the most common type of white blood cell.

Genetic A condition caused by abnormal genes (may be inherited).

GFR Glomerular filtration rate is a test that shows how well the kidneys are working.

Haematology The study of blood and blood disorders.

Haemoglobin The substance in red blood cells that carries oxygen around the body.

Histopathology The study of body tissues.

Hormone A substance made by a gland and carried in the bloodstream to parts of the body where it has a specific effect on the way the body works.

Immune system The body's defence against infection, disease and foreign substances.

Immunology The study of the body's immune system, which fights infection.

Immunophenotyping A test to identify particular proteins in the cells to help find out which type of cell has become cancerous.

Immunosuppressive Lowering the body's ability to fight infection.

Intramuscular (IM) Into a muscle.

Intrathecal (IT) Into the spine, usually by lumbar puncture. See also lumbar puncture.

Intravenous (IV) Into a vein.

Lumbar puncture (LP) This test can be done to diagnose, prevent or treat disease. The fluid that surrounds the brain and spinal cord is called cerebrospinal fluid (CSF). During the test, some CSF is removed by putting a needle into the lower back and the fluid is then examined in the laboratory.

Lymph A clear fluid that is part of the body's defence against infection. It is carried around the body in a network of lymphatic vessels.

Lymphatic system Part of the circulatory system. It consists of a network of vessels that carry a clear fluid called lymph in the direction of the heart. Excess fluid (lymph) in the tissues is drained by the lymphatic system into the bloodstream. It also defends the immune system.

Lymph nodes Small bean-shaped structures found along vessels in the lymphatic system. They become enlarged due to infection or cancer.

Lymphocyte A type of white blood cell that fights infection.

Malignant Cancer. It can spread to other parts of the body.

Metastases Tumours that have spread from the first (primary) tumour into another part of the body. Also known as secondary tumours.

MIBG scan It is usually done in children who have a diagnosis of neuroblastoma. It involves a radioactive substance being injected into the bloodstream and the scan being taken the next day. This will show up any areas of tumour in the body.

Microbiology The study of germs.

MRI scan This uses radio waves and a powerful magnet linked to a computer to take detailed pictures of areas inside the body. These pictures can show the difference between normal and diseased tissue.

Nausea Feeling sick.

Neuro- To do with the nerves or the nervous system.

Neutropenia or neutropenic Low levels of neutrophils.

Neutrophils White blood cells that fight infection.

Oedema Swelling caused by fluid.

Oncology The study and treatment of cancer.

Ophthalmology The study of the eyes.

Oral To do with the mouth.

Osteo- To do with bones.

Paediatric To do with children.

Palliative Relief of a symptom (for example, pain) rather than cure of the disease.

PET scan Positron emission tomography. This scan is normally done in children who have Hodgkin lymphoma. A very small amount of a radioactive substance is injected into the bloodstream, which can show up cancer cells on a scan.

Platelet A type of blood cell that helps the blood to clot.

PRN Medicines to take when required.

Prognosis The expected outcome of a disease and its treatment.

Prosthesis An artificial replacement for a missing or damaged part of the body, such as a bone or heart valve.

Pulmonary To do with the lungs.

Pulmonary function tests Tests that measure how well the lungs take in and breathe out air and also how well they move oxygen into the bloodstream. Your child breathes through a mouthpiece connected to a special machine called a spirometer.

Radiotherapy The use of high-energy X-rays to destroy cancer cells.

Red blood cells Blood cells that carry oxygen around the body. The part that contains iron called haemoglobin gives blood its red colour.

Refractory Resistant to treatment.

Relapse The return of a disease after previous treatment.

Remission There is no evidence of the disease being present, using the available tests.

Renal To do with the kidneys.

Sarcoma A tumour that forms in bone, muscles, fat or cartilage cells.

Stem cell Special cells that can turn into many different types of cells.

Subcutaneous (SC) Under the skin.

Therapy Treatment.

Thrombocytopaenia Low levels of platelets in the blood leading to bruising and bleeding.

Total parenteral nutrition (TPN) Giving nutrients into a vein when a child is unable to take food in the normal way (through the mouth).

Ultrasound A test that uses sound waves to examine the tissues inside the body.

White blood cells Blood cells that defend the body against infection.

X-ray An image that helps a doctor see the inside of the body.

Questions to ask your child's doctor or nurse

Here is a list of questions that you might like to ask your child's doctor or nurse. There is also some space for you to write down your own questions if you wish. Never be shy about asking questions. It is always better to ask than to worry.

What type of cancer does my child have? Where is it?

What tests and investigations does my child need?

What treatment choices are there?

Does my child need more than one type of treatment?

Is this the best treatment for my child? Why do you think so?

How long will treatment last?

Will my child be cured and recover?

What are the chances of the treatment working?

How and when will we know if the treatment has been a success?

What side-effects can my child expect in the short term?

Are there any long-term side-effects?

Will treatment affect my child's fertility in the long run?

How can we help our child before and during treatment?

Does my child need to eat special foods?

Can accommodation be arranged for us while our child is in hospital?

Should we tell our child that he/she has cancer?

What happens if the cancer comes back?

What happens if my child cannot be cured?

Are there any counselling or support services for parents?

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Parts of the booklet have been adapted with permission from the publication Children and Young People with Cancer: A Parent's Guide, produced by Children's Cancer and Leukaemia Group (CCLG) – the UK's leading provider of accredited cancer information for children and young adults, and their families, www.cclg.org.uk. CCLG accepts no responsibility for the accuracy of this adaptation.

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- *Cancer Trends No. 23: Childhood Cancer*. National Cancer Registry Ireland, 2014.
- *Cancer Trends No. 4: Cancer in Adolescents and Young Adults*. National Cancer Registry Ireland, 2010.
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- *Children and Young People with Cancer: A Parent's Guide*. Children's Cancer and Leukaemia Group (CCLG), 2014.
- *Children with Cancer: A Guide for Parents by Parents*. Cancer Plus and Irish Cancer Society, c.2001.

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Join the Irish Cancer Society team

If you want to make a difference to people affected by cancer, join our team!

Support people affected by cancer

Reaching out directly to people with cancer is one of the most rewarding ways to help:

- Help people needing lifts to hospital by becoming a volunteer driver
- Give one-on-one support to someone newly diagnosed with cancer as part of our Peer Support programme
- Give information and support to people concerned about or affected by cancer at one of our hospital-based Daffodil Centres

Share your experiences

Use your voice to bring reassurance to cancer patients and their families, help people to connect with our services or inspire them to get involved as a volunteer:

- Share your cancer story
- Tell people about our services
- Describe what it's like to organise or take part in a fundraising event

Raise money

All our services are funded by the public's generosity:

- Donate direct
- Take part in one of our fundraising events or challenges
- Organise your own event

Contact our Cancer Support Line on Freephone 1800 200 700 if you want to get involved!

Did you like this booklet?

We would love to hear your comments or suggestions.
Please email reviewers@irishcancer.ie

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